

# St. Louis Meets Needs Of Children With Chronic Treatable Disease

by Dr. Thomas Aceto

For the past quarter of a century, I have had the opportunity to care for children and adolescents who have serious, chronic, treatable disease, both as a pediatric endocrinologist and as a medical administrator. My definition of "serious, chronic, treatable disease" is this: *Serious* — Requiring a team of health care professionals; *Chronic* — Of many years duration; eg., three to a lifetime.

*Treatable* — Including drugs, surgery and counseling

*Prognosis* — Often not cured, but with therapy, patients look, feel, act better and become functional adults. Without therapy, many will not function, nor will they survive.

There are children in St. Louis with serious, chronic treatable diseases where I think the health care system is doing a reasonable job of meeting their needs. One example concerns a hemophiliac who is subject to recurrent episodes of serious bleeding requiring frequent transfusions and help from a health team of professionals. Now the patient's care, including intravenous therapy, is given at home by parents, patients and visiting nurses. The fiscal support includes the following: Department of Health, Education and Welfare — Great Plains Regional

Comprehensive Diagnostic and Treatment Center; Missouri Crippled Children's Services; Bi-State Hemophilia Society; Missouri Hemophilia Program; and the Illinois State Hemophilia Program. However, the three organizations which absorb the cost are St. Louis University Hospital, Cardinal Glennon Memorial Hospital for Children/Sisters of St. Mary, and the St. Louis University School of Medicine.

The second group of children I think are making progress are those with learning disabilities. These children are problematic in identification, classification and management. Their testing is very time consuming, requiring approximately 20 hours of professional time per patient. Subsequent education and management plus re-evaluation are time consuming also.

In this state, as part of the tertiary care system, these children whose families have limited incomes can be evaluated and helped via the local school system. Fiscal aid is provided through the State of Missouri Regional Center, Missouri Crippled Children's Services, Missouri Medicaid, and Knights of Columbus. Again, absorbing the costs are Cardinal Glennon Memorial and the St. Louis University

School of Medicine.

Forming another group are those children with cancer. They need many medications, much laboratory re-evaluation, a full team of health care professionals and in some cases, major surgery and subsequent radiation. Generally these children are offered treatments on an ambulatory basis; however, there need to be periods of hospitalization occasionally. In these cases, the fiscal support comes from the Candlelighters, Leukemia Society, American Cancer Society, Tricia Phillips Children's Cancer Fund, Cardinal Glennon Memorial/Sisters of St. Mary and St. Louis University School of Medicine.

Another bright spot concerns the program for the mentally retarded adults. In the city of Cape Girardeau there is a remarkable program for mentally retarded adults who are capable of working. In that program are sheltered workshops, supervised recreation, supervised independent living, and transportation. The financial support for the program comes from the Social Security income of the individual client, contributions from the Knights of Columbus, Missouri Department of Mental Health, and United Way.

These are all examples of programs which offer some financial support for families who are medically indigent. Children with other serious, chronic, treatable diseases are not so fortunate. There is no fiscal support for the medically indigent except for the generosity of individual physicians and individual religious orders for the following:

1. Children with hypothalamic pituitary tumors
2. Babies and children who have been battered
3. Teenagers and young adults with complications of diabetes mellitus
4. Children with chronic inflammatory disease of the bowel
5. The multiply handicapped
6. Children with asthma

For some, virtually no fiscal assistance is available. This group encompasses teenagers with serious, chronic, emotional problems.

As we think about the home care of ventilator-dependent children and adults, let us remember that they exemplify the problems of a large group of children, adolescents and adults who have serious, chronic, treatable diseases, but nevertheless, are individuals who can contribute to society and can enjoy their lives. Currently, many of these people receive less than optimal care because of inadequacies in the funding of the health care system and in the health care providers. The problem requires additional changes such as redirection of crippled children's funds from the categorical. Third-party payment for ambulatory care, home care, and psychological support must be instituted. We need to make optimal health care a national priority and to view the needs of the medically indigent as a priority as well as the needs of children. ●